

# WHEN YOU LET GO, HIS HANDS ARE FREE

ESTHER BISSCHOPS, BEHAVIOURAL SPECIALIST

'S HEEREN LOO ZORGGROEP

WITH THE COOPERATION OF OLGA BENNINK, PERSONAL CARER



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### THE PROBLEM

Rick is a young man of 25 who has a moderate intellectual disability as well as autism. He is curious by nature and enjoys observing all manner of things. He is particularly fond of looking at red stoplights and trying on sunglasses. From a young age, Rick has displayed severe self-injurious behaviour on a daily basis. This behaviour is the reason for his admission to a residential institution. Rick hits himself in the face until he bleeds. He bangs his head against walls, furniture, or anything else in his vicinity including his carers. When he loses all control, he simply drops to the ground and bangs his head on the floor. There is a huge risk of brain and eye injuries, and the head banging is actually life threatening. Rick needs a lot of care. He must be attended by two carers at all times, who must protect him from ~~the consequences of~~ his self-injurious behaviour. Rick doesn't really want to hurt himself and tries to protect himself from his own hands by tucking them deep into his armpits. Carers aid Rick in this ~~kind of self-control~~ by holding onto his hands where they stick out of his armpits at his back. When the self-injurious behaviour becomes so extreme severe? that even three carers cannot protect him, he is restrained in a chair or on a mat.

Rick has been diagnosed with general anxiety disorder. He is on a high dose of medication which makes him very lethargic. Both Rick and ~~the entire system~~ everybody around him are stuck in a dead-end situation drained of all human dignity.

### IDIOGRAPHIC THEORY

Rick has a moderate intellectual disability as well as autism. This means he has difficulty understanding the world around him. Rick's view of the world is fragmented, and he cannot distinguish between major and minor matters.

In addition, his information processing is slow. Conversations with his carers often move too quickly for him. It can sometimes take him up to 30 seconds to respond to something. Because he doesn't respond immediately, information or questions are repeated over and over, frequently using different words. For Rick, all this is then new information, which requires additional time for processing, which he is simply not granted. All of this results in mutual misunderstandings between him and his carers, and this has been ongoing since his early childhood.

As a result, carers have required less of him regarding both his language and his cognitive skills. Carers seem to base their approach to Rick on that for persons with severe intellectual disability; Rick is given short and simple verbal instructions. Whenever Rick initiates a conversation it is cut short to avoid overburdening him. However, he is actually under-burdened when it comes to language and cognition because he is not being addressed at his true level. This under-burdening frustrates Rick. And makes him feel insecure: "I can't seem to do it and I'm not allowed to ask for it". The tension in his head and body grows until he expresses it by hitting himself on the head. This is the first stage of his self-injurious behaviour.

Another measure that is taken due to miscommunication is reducing his sensory input: because Rick has slow information processing, it is assumed that he can only deal with a small amount of stimulation. His daily programme has been cut way back, his bedroom and his living room have been turned into low-stimulus environments, his social and group contact have been minimised and his medication has been increased. Steadily, fewer and fewer basic human needs are being met. He is not living in an environment conducive to human dignity, he is not having any meaningful activities anymore and he can no longer take any care of himself.

The bleak and impoverished nature of his existence has only intensified his sense of frustration and insecurity. Rick feels that he isn't good enough, that he can't do anything right, and that he isn't being taken seriously.

He expresses this by hitting himself in the head more often and with more force or by banging his head on hard objects. This self-injurious behaviour is getting increasingly worse and results in ever larger wounds. Rick bangs his head against anything he can reach: the edges of plates, tables, chairs, doorjambs, carers, car doors, the showerhead, etc. People around Rick are horrified to witness this, and out of fear of serious injury it was decided to stop or control his self-injurious behaviour. Rick's hands are restrained.

During the day, he is often placed in a restraining chair or in a wheelchair with restraints. At night, he sleeps in restraints around his waist and wrists. Another kind of medication is used to make him dazed and docile. Carers used protocols detailing exactly what they must do in certain situations. Rick's daily programme and his environment are pared down even more, depriving him of even more basic human needs.

Controlling Rick's behaviour by any means necessary has become the goal in order to prevent him from severely injuring himself. After a lot of back and forth, it is decided to try Contingent Electric Skin Shock (CESS) therapy on him. It has an opposite effect on Rick. Instead of eliciting an aversion to hitting, he becomes even more afraid of his own hands than he already was. He can't even look at his hands anymore and keeps them tucked away in his armpits. He wants the arms of his clothes to come down over his hands, covering them, and a carer on either side of him to restrain both of his arms and hands. The second Rick is released, he immediately begins displaying severe self-injurious behaviour. This reinforces his carers' fears, which inspires even more attempts at control.

A negative downward spiral has been created. Rick's ever increasing insecurity and fear and his expression of thereof, but also his carers' ever increasing fear and desire for control are being mutually reinforced. When carers try to stop Rick's self-injurious behaviour, he now responds with aggression towards them, mostly by biting and butting his head against them. This ultimately leads to huge escalations during which both Rick and

his carers are in danger of serious physical injury. The carers' fears are only multiplying.

The situation has become completely deadlocked. Every single day is a cocktail of fear, aggression, control, and despair. We no longer see Rick as a human being, he is just a huge problem, full of aggression and fear.

## INTERVENTIONS

### INTERVENTION 1: PUTTING RICK'S NEEDS AND DESIRES FIRST

Regarding Rick as a human being with needs and desires is at the core of our interventions. We no longer allow any challenging behaviour to determine the rest of his day. Rick is put on an intensive programme that challenges him and is designed to literally fill his thoughts and both of his hands. Rick starts work in a forest. Carers aid him in this as Rick keeps his hands in his armpits at first. The carers are creative, they roll up his sleeves, put a branch in the part of his hand sticking out of the back of his armpit, and tell him to take it away. Rick stagnates a lot, and drops to the ground, but his carers immediately help him back up and the activity continues. Rick is included in normal daily activities such as buying groceries and helping to set the table. He sits in a normal chair. In his free time, he can choose what he wants to do: watch red traffic lights and take train rides. After a time, Rick moves to a residential facility, the Very Intensive Care Workhome, where he can arrange and decorate his own room however he likes. He shares a living room with an open kitchen and a garden with his fellow residents. All activities are performed together, while Rick's main carer remains in his close proximity.

### INTERVENTION 2: STIMULATING VERBAL COMMUNICATION

We believe that all behaviour is a form of communication; Rick wants to tell us something with his self-injurious behaviour. Our goal is to find a means of communication that is more acceptable; speech, for example

Intervention number two is therefore aimed at stimulating verbal communication. The team is given detailed recommendations for interacting with Rick: be very patient, wait until Rick responds, don't add any new information until he responds, listen carefully to what he says, and give him clear and concrete answers to his questions. An example: Rick has a lot of CDs, sometimes he wants to get a new one and sometimes he wants to tell carers that one of them is broken. When he asks : "CDs?" the carer will repeat this and then wait patiently instead of assuming he/she knows what Rick meant. This gives Rick the opportunity to tell carers exactly what he wants to about his CDs and miscommunication and misunderstandings are avoided. Carers have only to listen and to nod.

### **INTERVENTION 3: MORE FREEDDOM**

We believe that the existing, ineffective patterns of action and reaction will be broken when we no longer focus on the self-injurious behaviour itself, but instead on Rick as a human being, with needs and desires, such as freedom.

To give both Rick and his carers more freedom, the action protocols are dropped. In their place, guidelines and ground rules are introduced which give Rick and his carers room to manoeuvre and experiment together. The daily programme is no longer set in concrete and detailed down to the minute, but now consists of broad lines, with blocks of time dedicated to self-care, work, housework, and free time. These blocks of time recur in the same order every day and the activities are also mostly the same, but they can vary. Rick is given more say in his own care by allowing him to choose among the structured activities in the blocks for housework or free time. With the help of his carers, he hangs up the corresponding pictograms. The deal is: whatever activity is on the pictogram will always proceed. Rick begins to trust his programme and his carers, who always make sure that the activities are successfully completed.

To allow Rick to take part more fully and consciously in activities, most of his medication is reduced.

#### **INTERVENTION 4: LETTING GO OF RICK LITERALLY AND FIGURATIVELY**

After a few months, both Rick and the team are ready to have his carers let go of him, he will no longer be put in restraints. Rick puts his own clothes on normally, putting his hands all the way through his sleeves so he can use them. Even when Rick starts hitting himself, the carers do not grab his hands. We trust Rick: he is in charge and can tell us what is important to him. Carers discuss every activity with him ahead of time: what he will be doing, where, with whom, and how. They will also agree on which parts Rick will be doing and which parts his carer will be doing. Together, they will bring the activities to a successful close. Rick is also regularly reminded that he can always ask for help, because he can speak very well.

The insecurity and frustration we observed in Rick, make way for anger at first: Rick is extremely angry at his carers because he now must do more by himself. During the first three weeks, he continuously hits himself extremely hard and often on his cheekbones. But he no longer drops to the ground to hit his head on the floor, as he quickly notices that his carers will no longer help him back up: Rick has hands for that. During this phase, we realise more and more that Rick is a grown man who, with the help of his carers, can communicate what he wants and can take care of himself. This realisation allows the team to begin to trust Rick and give him more freedom, step by step.

#### **RESULTS**

Rick's expressive communication skills have resumed developing again. His language use develops from two-word sentences to complete sentences.

Rick is gathering a succession of good experiences with his carers, which allows him to start trusting in other people. Rick is proud of what he can do by and for himself. His self-confidence is growing, which is reducing his insecurity.

Rick now has a say in his own life. He can make choices and decisions, and this increases his satisfaction levels. He alone determines which activities are worthwhile and meaningful to him.

Thanks to the reduction in his medication, Rick is now walking upright and showing interest in what is going on around him. His information processing is also faster than it was.

Rick is living a more “normal” life. He takes the train to work, goes for walks, does the grocery shopping, and eats without his carers’ help. He often relaxes his hands and allows them to drop to his sides.

He is no longer put in restraints. The use of restraints have been stopped.

His self-injurious behaviour has sharply declined; there are periods in which there is no such behaviour at all. When it does occur, he does far less damage to himself than previously.

Rick is experiencing that his body can also be a source of pleasure.

His aggression toward others, the biting, grabbing, and scratching of carers rapidly declines, and after a few weeks has completely stopped.

## LESSONS LEARNED

We have learned that first, we must find out who the client is as a person, and that we must make his disability or diagnosis subservient to that. A client’s potential should be the starting point to organise as normal a life as is possible. The client’s parents, relatives, and friends are essential allies in this process. They can often easily tell you what a client likes or what is important in the client’s life.



We also learned how important it is to have faith in your client and in one another. However difficult the situation is, keep believing in, and holding onto the conviction that there is always a way to improve a client's quality of life.

Our final recommendation: have regular discussions with the team about why certain interventions were chosen, what perceptions and theories that choice was based on, and what the intended result is. This is how you can anchor knowledge and expertise in the team. That is especially important when the client and the team experience a relapse. Even when it seems incredibly difficult: keep going. Don't fall back on the old interventions in panic after a relapse but stick to the new interventions and the daily programme that were proving helpful. It takes a great deal of courage and fortitude to do this, both on the part of carers and the support team, and you will all need to practice common sense, and to look very carefully for potential possibilities and risks.

## CONCLUSION

This was the case: When You Let Go, His Hands Are Free. We hope that we may have provided some inspiration for your own workplace.

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